My Daughter’s TSC Story: Triumphing Over Seizures

Sabril (Vigabatrin): Before and After Approval by the FDA

TSC Clinics Up Close

Research Update: Biomarkers for TSC and LAM
Summer is definitely in the air, and that means things are incredibly busy at the national offices of the Tuberous Sclerosis Alliance. It also means the current Fiscal Year will soon end on June 30, 2010. Therefore, I want to start by thanking outgoing Board Chair Celia Mastbaum for her incredible leadership, stewardship and compassionate dedication to the organization. Celia served as Vice Chair last year, Chair this year and will also continue to support the TS Alliance as Immediate Past Chair in the coming months, leaving an impressive imprint on how we operate.

I also want to salute the dedication of several board members whose terms are coming to an end: Terry Elling, Tommy Lindsey, Rob Thurston and Chris Sheffield. As most of you probably know, serving on the Board of Directors can almost be a full-time job, and all these individuals have helped the organization move forward in their own special ways. Thanks so much for all you’ve done on behalf of our constituents, their families and in our search for better treatments and a cure.

Spring and summer also mark the beginning of the TS Alliance’s Step Forward to Cure TSC walkathon season! This year will feature more than 30 walks taking place across the country, most in May/June, but a few in April and a few this coming fall. The TS Alliance certainly values the significant funds raised by these events, but the board and staff have also come to realize the important role the walks play in bringing together individuals and families for companionship, support and as a true “community” that is working toward a common goal. We often hear how for some people, the walks are the only time of the year they are able to be with others affected by TSC, and we are very proud Step Forward to Cure TSC has grown so much over the years. Thanks to all of you who spearhead and run the walks, to our national sponsors Lids and Lundbeck, and to each and every one of you who attend. No matter how much you raise, just being there makes a true difference to others.

Please know the TS Alliance is well aware that the current economy continues to pose challenges not only to our ability to raise funds, but also to all of you in your daily lives. As a result, the board and staff have been discussing the timing of the next National TSC Conference. You can probably imagine this effort requires significant additional fundraising to help supplement the cost to attendees as well as a huge staffing commitment. Because of these financial challenges to the organization – and the cost to our constituents who would attend, we will re-evaluate the National TSC Conference in December 2011. We will certainly keep everyone updated.

While we realize conferences offer the optimal educational opportunities, the TS Alliance is providing cost-effective ways to share important breakthroughs in research and clinical care and give you support when needed, including:

- **Research Teleconference Series** – these are free of charge and offered periodically throughout the year. For those unable to attend, we post the audio files on our website so you can listen at your convenience.
- **Town Hall Meeting Educational Series** – these new local Community Alliance events bring together those affected by TSC with major researchers, TSC Clinics and clinicians. Look for more information on these elsewhere in this issue.
- **Perspective** – this magazine continues to be one of our best vehicles to keep everyone updated, particularly on current research efforts and breakthroughs.
- **Website** – www.tsalliance.org continues to offer the most current information available and I encourage you to visit it often as we are constantly updating the site and adding new features.
- **Director of Advocacy & Education** – Dena Hook is available to help support you in a number of ways. Many of you know her because of her expertise in educational advocacy, but she also offers much more including being able to help you find medical care, put you in touch with others in your area for support, host monthly online sibchats as well as adult teleconferences and is available to just listen to you when needed.

Finally, I want to thank all of you who took the time to complete our recent Online Constituent Survey as it will provide a good blueprint for the organization’s efforts to address the needs of our TSC community in the future. We value all of your thoughts, suggestions and even the complaints! Your feedback is important.

I hope you enjoy a wonderful summer and please remember to continue to spread awareness of TSC. Join me in making a pledge to tell one additional person per week about tuberous sclerosis complex, whether it’s a chance meeting with a new person, sharing with an old friend through Facebook or contacting your local newspaper. Let’s continue to fight – together – for a cure.
On April 11 the 9th Annual Comedy for a Cure took place at Boulevard3 in Hollywood, CA. The evening kicked off with Hosts Patricia Heaton and Leeza Gibbons along with a presentation from our very own Dr. Vicky Whittemore who gave a brief update on current TSC research and the hope that lies ahead. As always there was the fabulous live auction hosted by our long-time supporter and auctioneer Damon Casatico and outstanding comedic performances by Ray Romano, Larry Miller, Mike Polk, and Jeff Allen. This year’s Honorees were Craig and Cindy Cunningham of C&C Market Research. Together everyone helped in raising $250,000 for the TS Alliance! A very special thank you to our event Co-Chairs Dr. Rick and Jennifer Glassman, Auction Chair Julia Cohen, and the planning committee.

On January 24 the 17th Annual Joey Holuboeys TSC/Pampered Chef Charity Auction took place at the Cudahy Family Library in Cudahy, WI. This year’s auction raised its most ever, $3,500! Thank you to Lundbeck for sponsoring this year’s auction and a very special thank you to Pam Sztukowski for
her tireless and many, many years of support in raising funds and awareness of TSC in memory of her son Joey.

On February 24 the 9th Annual DC Food & Wine Tasting Event took place at Morton’s, the Steakhouse raising more than $105,000. The evening began with event Co-Chairs Julie Blum and John Poutasse who thanked Morton’s and our presenting sponsor, the Winifred M. Gordon Foundation. A special video was shown featuring one of our local Metro DC TSC families – Rob and Lisa Moss, whose son Evan has TSC. Dr. Vicky Whittemore, the TS Alliance’s Chief Scientific Officer, gave the crowd an update on the exciting state of TSC research across the nation and the President & CEO Kari Luther Carlson then helped honor PhRMA CEO Billy Tauzin for his national leadership in advocating for access to medicines to treat all illnesses, particularly lesser known diseases like TSC. Thank you to everyone for making this event such a positive experience.

TS Alliance Announces 2009 Volunteers and Community Alliance of the Year

Each year, the TS Alliance honors four individuals for their outstanding commitment and dedication to the organization and one Community Alliance for its outstanding commitment to community service, increasing awareness of TSC in their local area and their dedication to furthering the mission of the TS Alliance. Recipients are recognized during the week of the March on Capitol Hill at the Board of Directors and Annual Leadership Meeting.

NEW: 2010 TS Alliance Town Hall Meetings

Join Us for Educational Opportunities Across the Country

Plan now to attend a town hall meeting to make stronger connections with peers, researchers, and clinicians in your community. Don’t miss this opportunity to meet these dedicated clinicians and researchers who care for hundreds of individuals with TSC and other families living with TSC.

Who Should Attend?
- Parents and caregivers.
- Adults with TSC.
- Professionals who support people who have TSC.
- Anyone who wants to learn more in a relaxed, open and casual town hall setting.

What Will Be Covered?
- Update on current research in TSC.
- Explanation of the clinical trial process.
- How to make informed decisions about participating in future clinical trials.
- How basic research translates into clinical care.
- Upcoming community activities.
- Question and answer period.
- Feedback encouraged!

Dates and Locations
- July 24: Nashville, Tennessee
- July 31: Cleveland, Ohio
- August 1: Houston, Texas
- August 14: Fairfax, Virginia
- August 21: Mountain Brook, Alabama
- October 23: Boston, Massachusetts
- September 24: Cincinnati, Ohio
- September 25: Pittsburgh, PA
- TBD: California
- TBD: Georgia (Atlanta)
- TBD: Illinois
- TBD: Minnesota
- TBD: New York
- TBD: Pennsylvania (Philadelphia)

For more information please contact Dee Triemer at (800) 225-6872 or dtriemer@tsalliance.org.

The TS Alliance Town Halls are supported by an educational grant from Novartis. Per our corporate relations policy, the TS Alliance maintains complete control of the content and materials related to these Town Hall meetings. The TS Alliance selects the speakers and per our privacy policy no outside organization has, or will ever have, access to mailing lists or private information.

Special Events

TS Alliance

Announces 2009 Volunteers and Community Alliance of the Year

Kari Luther Carlson (far left) and Jenny Smiley (far right) with Volunteers of the Year Missy Anderson, Roxanne Rios, Susan Campbell and Ron Hefron.

NEW: 2010 TS Alliance Town Hall Meetings

Join Us for Educational Opportunities Across the Country

Plan now to attend a town hall meeting to make stronger connections with peers, researchers, and clinicians in your community. Don’t miss this opportunity to meet these dedicated clinicians and researchers who care for hundreds of individuals with TSC and other families living with TSC.

Who Should Attend?
- Parents and caregivers.
- Adults with TSC.
- Professionals who support people who have TSC.
- Anyone who wants to learn more in a relaxed, open and casual town hall setting.

What Will Be Covered?
- Update on current research in TSC.
- Explanation of the clinical trial process.
- How to make informed decisions about participating in future clinical trials.
- How basic research translates into clinical care.
- Upcoming community activities.
- Question and answer period.
- Feedback encouraged!

Dates and Locations
- July 24: Nashville, Tennessee
- July 31: Cleveland, Ohio
- August 1: Houston, Texas
- August 14: Fairfax, Virginia
- August 21: Mountain Brook, Alabama
- October 23: Boston, Massachusetts
- September 24: Cincinnati, Ohio
- September 25: Pittsburgh, PA
- TBD: California
- TBD: Georgia (Atlanta)
- TBD: Illinois
- TBD: Minnesota
- TBD: New York
- TBD: Pennsylvania (Philadelphia)

For more information please contact Dee Triemer at (800) 225-6872 or dtriemer@tsalliance.org.

The TS Alliance Town Halls are supported by an educational grant from Novartis. Per our corporate relations policy, the TS Alliance maintains complete control of the content and materials related to these Town Hall meetings. The TS Alliance selects the speakers and per our privacy policy no outside organization has, or will ever have, access to mailing lists or private information.
From the Board Chair . . .

As the TS Alliance’s current Fiscal Year comes to an end, I am writing my last letter to you as Chair of the Board of Directors. While the economy has been challenging for many of us over the last few years, I’m quite pleased that the TS Alliance has not only weathered the financial storm admirably, but has also had impressive successes, particularly in advancing our research initiatives. I am ending my term very satisfied with how the organization is positioned for the future.

I’m very pleased to announce that David Parkes will be Board Chair in the new fiscal year, supported by Vice Chair Henry Shapiro, Secretary Matt Bolger and Treasurer Rita DiDomenico. All of these current and prospective officers of the Board bring strategic strengths and skill sets which will help the organization advance its mission and achieve its goals. I know you will all join me in supporting them in their endeavors in the coming year.

I’d also like to welcome two new board members, Keith Hall and Ted Mastroianni. Keith has been active in raising awareness about the issues faced by adults with TSC and in participating in clinical trials. Ted, who joins us in honor of his grandson Makai, has more than 35 years of experience in the public arena, and offers the organization expertise in management, finance, fundraising and organizational development.

Please join me in also thanking the following board members whose terms are ending this year: Terry Elling, Tommy Lindsey, Rob Thurston and Chris Sheffield. On behalf of the board and our constituents, I take great pleasure in extending my utmost appreciation and gratitude for their commitment and unwavering dedication to guiding the TS Alliance with their expertise. I certainly believe with all my heart that volunteers – whether they serve as board members, Community Alliance leaders or on the local level – are this organization’s lifeline. We simply could not move forward without you.

I continue to marvel at the pace of TSC research as we truly are finding better treatments for all TSC individuals, while we continue to search for a cure. This fiscal year, we sponsored our third International TSC Research Conference and instituted a series of free research teleconferences for our constituents on variety of topics. These educational calls have proven to be very popular and allowed the organization to service a large number of our constituency in a very cost-effective manner.

I am very proud of the work our organization has done on behalf of everyone touched by TSC such as my son Matthew, who serves as my daily inspiration. While this is a personal fight for me, I am still humbled by the grace and determination that the members of our community exhibit in facing the daily challenges of this disease. I am taking away so much more than I could possibly give when I read our daily listserv, speak to members of our community and interact with our medical and scientific professionals. But the most important take away I have from the privilege of serving this community is that there is true hope of a cure just around the corner...

Celia Mastbaum
celmast@aol.com
(732) 580-6467
Editor’s Note: Jamie Youngblood Holland is 33 years old and has been seizure-free since November 26, 2008. She made the brave decision 18 months ago to undergo brain surgery at the Cleveland Clinic. This is her story about living with tuberous sclerosis complex and coping with seizures.

As a parent of a child with TSC, it is very painful to endure at times. I can’t even imagine how my daughter Jamie felt all those years dealing with the seizures and the drugs. I’m sure anyone reading this can totally identify with us. My daughter was diagnosed at 3 years of age. She was given medications then and still is on Felbatol and Trileptal today. When the seizures started, she was placed on chewable Dilantin, which controlled her seizures for awhile. Toward the age of 8, we noticed an unusual staring, clapping of hands, and an audible noise I can’t describe. They didn’t last very long – just a couple of minutes – but afterward, she was always in a state of confusion, remembering nothing. These were complex partial seizures.

With increasing seizures, the medication roller coaster began, and eventually Dilantin stopped working. The complex partials were very difficult to deal with as a teenage girl as the last thing you want to happen is to have a seizure during school. But it definitely happened.

Jamie was never too self-conscious about the seizures. I think because she always participated in every activity you could dream of. She was just like every one else, except she had seizures and took loads of medication for it. She was in Girl Scouts and little league softball, went to summer camp for years, played in the band and high school sports, and worked numerous jobs. Her philosophy was, “When I meet new people, I just tell them. I might have a seizure sometimes, but I will be OK in a few minutes.”

She had an excellent attitude about the circumstances. However, there were definitely frustrating times. But overall, she functioned in society very well despite the barriers.

At age 19, the grand mal seizures began. The first one was so strong I called an ambulance as I was petrified. Her neurologist suggested seizure surgery evaluation at Johns Hopkins Hospital, in Baltimore, MD. This was in 1996, when she was 20 years old.

The doctors presented their findings to me and to Jamie. Keep in mind, the idea of shaving her head and cutting part of the skull with a surgical saw to remove a section of her brain was not appealing to Jamie at the time. I told her it was her decision. She declined.

From age 20 to 31, she tried every medication under the sun. Dilantin, Depakote, Gabatril, Keppra, Lamictal, Neurontin, Tegartol/Carbartol, Lyrica, and Topamax are some I remember. Presently, she takes Felbatol and Trileptal – half the amount post-surgery than she previously needed. TSC required a combination of medications,
and side effects would vary, including mood swings, weight gain and weight loss. Sometimes they would slow the seizures, and sometimes they didn’t phase them.

It was very exasperating for her, living in the adult world and trying to maintain employment was becoming more and more difficult. At age 24, she obtained a job with the Department of Veterans Affairs as a file clerk. I also work at the same campus, so I took her to and from work every day since she could not drive. As her seizures became more frequent, the medication continued to increasingly cause her to live in a constant “fog.” Some days were better than others. Bottom line: the meds just didn’t work any more.

The near toxic level of medications also slowed her thought processes – even her speech was slower. But still, facing these barriers, she kept going, working and trying to function the very best that she could.

Her seizures had worsened over a 30-year period. It was a slow progression, but the last 10 years had become increasingly dangerous. The grand mal seizures were increasing in number, and the postictal psychosis was horrible. Her neurologist suggested she go for surgery evaluation again since technology and TSC research had advanced tremendously.

It took Jamie several years to finally determine that she’d had enough and was ready to take the risk. She was tired of the emergency calls for an ambulance, the restraints, and injections of valium to stop the postictal psychosis. It took Jamie several years to finally determine that she’d had enough and was ready to take the risk. She was tired of the emergency calls for an ambulance, the restraints, and injections of valium to stop the postictal psychosis.

The decision was final. In August 2008 she was admitted to the Cleveland Clinic epilepsy monitoring unit as an inpatient for around-the-clock care and video monitoring while all meds were stopped and they did continuous EEG monitoring, CAT scans, PET scans, MRS, and SPECT with injection. After a few days, the seizures were happening quite often, and they recorded enough information to present to the clinical team to determine if she was a surgery candidate. Some of the video was quite gruesome. They attempted to let me see the recordings, but I couldn’t watch because of the intensity of the grand mal seizures on no medication. It was not pleasant. The blessing was she never remembered anything. We were there 9 days.

Within a week, we learned she was definitely a seizure surgery candidate, and the team felt very positive they could help her. This was an answered prayer. The seizure focus was the same as it had been 13 years earlier: the left temporal region. They had identified the exact spot, but much more detailed testing would be required. We went back on November 16, 2008 with her first surgery scheduled on November 19. This would be to implant electrodes within the brain, 3 on each side, (depth electrodes – 1 was a strip electrode) to monitor from inside the focal area. This involved shaving the sides of her head, drilling holes to implant the electrodes. She was still off of her medication so they could record the seizures from the inside to be absolutely positive where to operate. During this time, horrible seizures were happening. I had never seen a generalized seizure before in this controlled environment. The same thing happened during the evaluation in August. It was like a horror movie. It really is not something a mother wants to see. To tell you the truth, I had to leave the room.

The depth electrodes were in for 7 full days. It was a very difficult, emotional, uncomfortable, and painful 7 days. There were days that she begged me to make it stop. I couldn’t. I kept telling her, it will all be over soon. That wasn’t much to offer, but I was in a stunned state of mind at times. On November 26, 2008, Jamie had a left temporal lobectomy with a resection of the mesial structure and mesial temporal tuber removing the left hippocampus.
There were 3 tubers lined up behind each other. They only detected one with all of the advanced testing, but when the surgeon went in, he said there were two more behind the first one. I believe God used the surgery to give my daughter a new life—a seizure-free life! I am so excited to be a witness!

Jamie has not had a seizure since that day. Her medication is cut in half. She will stay on meds forever, but she no longer lives in a fog. Her recovery and rehabilitation was a lot of hard work for her, but to see her today, you would never know she had serious brain surgery 18 months ago. Her only deficit is reading comprehension and memory issues. Her speech therapist said this will continue to improve in time.

Her doctors said it takes several years for the brain to completely heal itself and reroute to use the memory function on the right side. She went back to work 3 months after surgery. She drives now. She has a completely new personality. The inner Jamie had been stifled for so many years due to the drugs and trauma of the seizures.

There are so many more details to her story, but I wanted the TSC community to know, there are happy endings. Moms and Dads, be strong for your child, there is hope. Technology is advancing every day. With faith in God—anything is possible. My daughter is living proof. Jamie was married to a wonderful man in May 2007. She works full time, drives herself to and from work now, she can go to Walmart everyday if she wants to! They have a beautiful house with 2 cats...they are her babies. Jamie is very creative. Her yard is full of flowers and not a weed in site. Her new life is a gift from God. I and our family were blessed with seeing her transformation.
If your child is missing school because of his/her behavior and the school’s answer is to send him/her home, a behavior evaluation should be performed to address these behaviors. Taking your child out of the learning environment is not addressing his or her educational needs. When children are out of school they can’t be exposed to the general education curriculum, let alone progress in it, which is a legal requirement under the Individuals with Disabilities Education Act 2004 (IDEA).

When a child is in school and the behavior interferes with his/her learning and/or the learning of others, there should be a formal behavior intervention plan placed in the student’s individual education plan (IEP). Since behavior is a common manifestation of individuals with TSC, a functional behavior assessment (FBA) should be done to determine what is triggering the behaviors. A FBA will give much-needed information to develop a positive behavior intervention plan (BIP).

To complete a FBA, information must be gathered to determine what the cause is for the behavior. This information needs to be gathered through:

- Health and medical issues
- Education evaluation testing
- Direct observations (by more than one individual and in different settings)
- Home environment (parents, friends, relatives)

Once information has been gathered the questions to be answered are:

1. What behaviors do we want to modify or change?
2. Where does the behavior occur?
3. In what environment is the behavior occurring?
4. What is the common antecedent to the behavior?
5. Does there seem to be a pattern?
6. What is the trigger (reinforcer) for the behavior?
7. Why is the behavior occurring?
8. What more appropriate behavior can be taught to replace the inappropriate behavior?

This process cannot be done in an hour and be gathered by one person. There needs to be information gathered in structured and unstructured environments. Parents and medical health professionals should be part of the FBA process to know exactly what is causing the behaviors. When dealing with individuals with TSC, ruling out medical issues first will be of utmost importance. Medications, seizures, and other medical issues must be considered. Sometimes, simple medication changes can have a major effect on behaviors.

**Behavior Intervention Plans**

Behavior intervention plans (BIP) must be in writing and placed in the student’s IEP. Just talking about putting a BIP in place does not make it happen. If there is a formal plan written and placed on a formal document, then the student is protected under the law. IDEA 2004 includes provisions in the law to protect a student with behaviors that are manifestations of the child’s disability.

A BIP should minimize the influences that cause the behavior. It should provide instruction in appropriate behavior to replace the problem behavior and identify accommodation and supports to promote the student’s success in social and academic areas. A BIP should be designed to teach social and problem-solving skills and should also address medical, physical or emotional needs.

Make sure the BIP:

- Is team-developed (including general educator input).
- Is based on the FBA.
- Is in writing and incorporated into the IEP.
- Modifies the antecedents before a behavior can occur.
- Strategies to strengthen and teach appropriate behavior.
- Modifications in curriculum or classroom expectations.
- Provides a crisis intervention plan, if needed.

The purpose of the BIP is to teach appropriate behaviors and keep the student in the school environment so they can be exposed to the general education curriculum and progress in it.

To learn more about FBA and BIP go to www.tsalliance.org and click on “For School Issues,” then scroll down to publications and choose “Behavior Issues and TSC” to download the publication.
Our daughter Emily, who is now 11 years old, was diagnosed at birth with TSC and was only seizure-free the first three months of her life. By the age of four she was having roughly 35-50 seizures a day. She had been on every anticonvulsant and had the Vagus Nerve Stimulator (VNS) implanted in 2003. We saw improvement with her seizures after the VNS was implanted, but she still had about 20 seizures a day. Without any more options for medication to treat her seizures, the doctors told us we needed to start considering brain surgery for Emily. It was a very difficult time in our lives with no more options and thinking we would have to put our daughter through brain surgery. My first thought was there has to be another drug we can try, or another kind of treatment other than surgery.

While talking to Emily’s neurologist about the kind of tests that she would need to do to determine if she was a candidate for brain surgery, he asked if she had ever been on vigabatrin. She hadn’t because I always thought it was used only for infantile spasms. I had just assumed that was the case, but her neurologist told us they had been treating individuals with complex partial seizures with vigabatrin and were seeing improvement. I had always heard about the bad side effects of the drug and was really scared.

We decided to give it a try and prayed that this drug would help her. We went home with a prescription for vigabatrin and I called everyone I knew whose child was on the drug and got the name of a pharmacy in Canada. I immediately faxed the prescription to them and called them with my credit card number. Within the week we had the tablets in our hands. We started seeing improvement in her drop attacks as well as her complex partial seizures within the first few weeks. During this time we were told she would have to have a special eye test performed to see if her vision was being affected by the vigabatrin. We never had the test done because we felt that the improvement in her seizures were more important than the side effects with her vision. The process of adding vigabatrin was very slow and I think we were a little more cautious because the drug was not approved by the Federal Drug Administration (FDA). It took us about a year to get to the level her neurologist recommended.

During that time we continued the process to see if Emily was a candidate for surgery by traveling to many different sites to get the most accurate testing completed. Emily’s seizures were getting worse. She was having grand mal seizures daily and her drop attacks were the worst we had ever seen. Vigabatrin was helping, but we had to give her valium on a weekly basis for the seizures and knew we needed to have the surgery as soon as possible.

Emily finally underwent two brain surgeries to separate her corpus callosum. This surgery was a success and got rid of the awful drop attack seizures. Emily is still having about seven complex partial seizures a day but it is an improvement compared to seven years ago. We had talked to her neurologist about taking her off vigabatrin mainly because we were worried about the side effects of her being on it for so long, but he really believes that it is helping her seizures.

Since vigabatrin was approved by the FDA in September 2009, we have continued with the medication. We have worked very closely with her neurologist to get all of the paperwork completed through the SHARE program through Lundbeck Pharmaceuticals in a timely manner. As with any other
There are many strict policies that both the drug manufacturer and physicians have to follow to continue to supply this drug. One strict guideline that needs to be followed is individuals should have an electroretinogram (ERG) performed every three months. The ERG is a special eye test that is done to see if a person is losing their peripheral vision due to a medication. This is also one of the main reasons the FDA had not previously approved vigabatrin.

We were very excited about the FDA approval of vigabatrin for many reasons. The cost was extremely expensive, and we always worried that the medication would not arrive in time. The pharmacy that we worked with in Canada was very good at calling us to remind us that we needed to refill the prescription, but that was not always the case. During this time I heard many stories of families running out of vigabatrin because of the mail system or circumstances out of their control. With the new SHARE program through Lundbeck Pharmaceuticals families are more at ease in knowing that their medication will be there. The SHARE program has been an effective means for the families to work closely with their child’s neurologist in order to get the paperwork required completed in a timely manner. The SHARE program has been excellent and they call to remind us that her prescription needs to be refilled and then they ship it out in time. The only problem that we have come across has been with our own personal insurance company taking care of the co-pay for the medication.

As I mentioned before the regulations regarding the use of vigabatrin requires an ERG test be performed every three months. I feel it is very important when you call your ophthalmologist office to schedule the ERG test that you state that this test is imperative that your child have as soon as possible to ensure that they remain on this drug to control their seizures, as well as informing them that it will need to be done every three months. Unfortunately, the ERG machine at our Children’s hospital was down for a month for repairs, which delayed the ERG test. During this time I was receiving letters from the SHARE program letting me know that she needs an ERG test done immediately or they might take her off the vigabatrin. We have completed the ERG and are now working with her neurologist and the ophthalmologist to ensure that the SHARE program receives the proper paperwork that states she has had the ERG completed. If you decide that your child cannot or you do not want to have the ERG test performed every three months, the neurologist needs to complete the ophthalmologist form and mark the box that says they will not have an ERG test performed. This will have to be completed every three months to ensure that your child will continue receiving vigabatrin.

As a parent of a child with tuberous sclerosis complex we have to make many tough decisions regarding her health on a daily basis. I hope that this article about our journey with Emily has been helpful. Someone asked me today how do I do it and I said, “Well, Emily has only me to survive this disease and I am here to fight it every inch of the way. If there is a medication that I feel will help her have a better quality of life, I will do it!”

Lundbeck SHARE Program

Information about Sabril and resources for healthcare professionals, patients and caregivers can be found at www.lundbeckshare.com. SHARE is a comprehensive resource for healthcare professionals and their patients with severe or uncontrolled epilepsies, providing:

- The latest clinical and product information from Lundbeck
- Tools and resources to aid patient education
- Specific initiatives to manage permanent vision loss associated with Sabril risk
- Prescription support and restricted distribution
- Programs to help with patient education and assistance
- Downloadable Seizure Diary

If you have questions regarding medical information or safety of Lundbeck products, call 1-866-209-7604 or send email to information@lundbeck.com.
March on Capitol Hill brings dozens of advocates to Washington, D.C.

On February 24, individuals and families coping with tuberous sclerosis complex (TSC) converged on Capitol Hill to advocate for increased federal funding for TSC. Our advocates held more than 360 meetings with Senators, Representatives and their staff members, urging them to support a $15 million appropriation for the Tuberous Sclerosis Complex Research Program (TSCRP) at the Department of Defense. Specifically, we asked our elected officials to sign onto bipartisan “Dear Colleague” letters that were circulated by Representatives Loretta Sanchez (D-CA) and Gary Miller (R-CA) in the House and Senators Sherrod Brown (D-OH) and Mike Crapo (R-ID) in the Senate. Our advocates shared their personal stories with their Members of Congress and clearly explained how greater federal investments in research can lead to new breakthroughs in our understanding of this complex disorder!

House and Senate Dear Colleague letters attract strong support from Members of Congress

Thanks in large part to our March on Capitol Hill, the Sanchez-Miller letter attracted the support of 90 members of the House of Representatives – a record number of signatures for this annual letter. In the Senate, the Brown-Crapo letter was signed by 22 Senators, exceeding last year’s number of signatures. The House letter was sent to the House Appropriations Subcommittee on Defense on March 22, and the Senate letter was submitted to the Senate Appropriations Subcommittee on Defense on April 8. The House and Senate Appropriations Committees are expected to act on the fiscal year 2011 Defense Appropriations bill in the coming months.

Although both House and Senate letters attracted a strong level of support, they do not by any means guarantee that the TSCRP program will receive an increase in funding above the $6 million appropriated in fiscal year 2010. The huge federal budget deficit will make it very difficult for Congress to approve any increase in funding for any federal programs. However, our advocacy efforts demonstrate a strong level of grassroots commitment to finding a cure for TSC, and it is our hope that Congress will respond with an increase in funding!

Our efforts could not have been possible without our champions in Congress who worked hard to secure support from their colleagues for these letters. Of course, this successful effort would have not been possible without the dedication of our advocates around the country who took the time to come to Washington, D.C. or who met with their elected officials back home.
TSCR P Letter

Senate Cosigners

CALIFORNIA
Barbara Boxer

CONNECTICUT
Christopher Dodd
Joseph Lieberman

GEORGIA
Saxby Chambliss
Johnny Isakson

HAWAII
Daniel Akaka

IDAHO
Mike Crapo
Jim Risch

ILLINOIS
Roland Burris
Richard Durbin

MICHIGAN
Debbie Stabenow

NEW HAMPSHIRE
Jeanne Shaheen

NEW JERSEY
Frank Lautenberg
Robert Menendez

NEW YORK
Kirsten Gillibrand
Charles Schumer

OHIO
Sherrod Brown

OREGON
Jeff Merkley
Ron Wyden

PENNSYLVANIA
Robert Casey

RHODE ISLAND
Sheldon Whitehouse

SOUTH DAKOTA
Tim Johnson

House Cosigners

ALABAMA
Artur Davis (AL-7)

ARKANSAS
Vic Snyder (AR-2)

ARIZONA
Raul Grijalva (AZ-7)

CALIFORNIA
Henry Waxman (CA-30)
Judy Chu (CA-32)
Laura Richardson (CA-37)
Gary Miller (CA-42)
Joe Baca (CA-43)
Loretta Sanchez (CA-47)

CONNECTICUT
Joe Courtney (CT-2)

Rosa DeLauro (CT-3)
Jim Himes (CT-4)
Christopher Murphy (CT-5)

FLORIDA
Alcee Hastings (FL-23)
Kathy Castor (FL-11)

GEORGIA
Hank Johnson (GA-4)
John Lewis (GA-5)
David Scott (GA-13)

HAWAII
Mazie Hirono (HI-2)

ILLINOIS
Bobby Rush (IL-1)
Luis Gutierrez (IL-4)
Melissa Bean (IL-8)
Janice Schakowsky (IL-9)

INDIANA
Andre Carson (IN-7)
Brad Ellsworth (IN-8)

IOWA
Bruce Braley (IA-1)
David Loebsack (IA-2)
Leonard Boswell (IA-3)

KANSAS
Dennis Moore (KS-3)

MASSACHUSETTS
James McGovern (MA-3)
Barney Frank (MA-4)
Stephen Lynch (MA-9)
William Delahunt (MA-10)

MARYLAND
Chris Van Hollen (MD-8)

MAINE
Chellie Pingree (ME-1)
Michael Michaud (ME-2)

MICHIGAN
Dale Kildee (MI-5)
Mark Schauer (MI-7)
Gary Peters (MI-9)
Sander Levin (MI-12)
John Conyers (MI-14)

MINNESOTA
Keith Ellison (MN-5)
Collin Peterson (MN-7)
James Oberstar (MN-8)

MISSOURI
Russ Carnahan (MO-3)

NORTH CAROLINA
David Price (NC-4)
Brad Miller (NC-13)

NEW MEXICO
Martin Heinrich (NM-1)

NEW JERSEY
Chris Smith (NJ-4)

Frank Pallone, Jr. (NJ-6)
Bill Pascrell, Jr. (NJ-8)
Rush Holt (NJ-12)

NEW YORK
Pete King (NY-3)
Carolyn McCarthy (NY-4)
Gregory Meeks (NY-6)
Joseph Crowley
Jerrold Nadler (NY-8)
Edolphus Towns (NY-10)
Carolyn Maloney (NY-14)
Eliot Engel (NY-17)
William Owens (NY-23)
Dan Maffei (NY-25)
Chris Lee (NY-26)

OHIO
Steve Driehaus (OH-1)
Charles Wilson (OH-8)
Marcia Fudge (OH-11)
Betty Sutton (OH-13)
John Boccieri (OH-16)

OREGON
David Wu (OR-1)
Peter DeFazio (OR-4)

PENNSYLVANIA
Robert Brady (PA-1)
Jason Altmire (PA-4)
Jim Gerlach (PA-6)
Joe Sestak (PA-7)
Patrick Murphy (PA-8)
Christopher Carney (PA-10)
Charles Dent (PA-15)
Tim Holden (PA-17)

SOUTH DAKOTA
Stephanie Herseth Sandlin (SD-At Lrg)

TENNESSEE
Steve Cohen (TN-9)

TEXAS
Ron Paul (TX-14)
Sheila Jackson Lee (TX-18)
Charles Gonzalez (TX-20)

VIRGINIA
Robert Scott (VA-3)

WASHINGTON
Rick Larsen (WA-2)
Jim McDermott (WA-7)

WISCONSIN
Tammy Baldwin (WI-2)
Thomas Petri (WI-6)
Steve Kagen (WI-8)

GUAM
Madeleine Bordallo (Guam-At Lrg)

Kari Luther Carlson
President and Chief Executive Officer

Gail Alexander
Senior Manager of Operations

Jaye Isham
Director of Advocacy and Education

Dena Hook
Director of Advocacy and Education

Mary Jane Perrat
Controller

Katie Smith
Science Coordinator

Bronia Svoysky
Staff Accountant

Dee Triemer
Community Outreach Manager

Vicky H. Whittemore, Ph.D.
Vice President and Chief Scientific Officer

All staff can be contacted by email or by calling the office toll-free phone number: (800) 225-6872. Staff members are available for assistance in finding resources and/or to answer any questions you may have. Note: To email a staff member, use First Initial Last Name @tsalliance.org or Info@tsalliance.org.

Contact Information

TS Alliance Staff

P E R S P E C T I V E
The Tuberous Sclerosis Clinic at Washington University – St. Louis, MO

The TS Clinic at Washington University opened in 2002 under the direction of Kevin C. Ess, M.D., Ph.D., a child neurologist and researcher at Washington University (WUSTL) with a special interest in tuberous sclerosis complex (TSC). The TS Clinic is open to children with TSC and is located at the St. Louis Children’s Hospital. When Dr. Ess moved to Vanderbilt University in 2006, Michael Wong, M.D., Ph.D. agreed to take over as the TSC Clinic Director. Dr. Wong is assisted by Administrative Coordinator Laura Graves; Nurse Coordinator Christine Immken, R.N., C.P.N.; and Community Alliance Volunteer René Friedel, who provides social education and support from the perspective of a parent with a child affected by TSC.

Mice with TSC and Seizures

Dr. Wong’s interest in TSC came about serendipitously when Dr. Ess’ research mentor and TS Alliance-funded researcher, Dr. David Gutmann, noticed that the mouse model of TSC he was studying also had seizures. Knowing that Dr. Wong was doing epilepsy research, he approached him with a proposition, “I’ve got mice with TSC who are having seizures… are you interested?” Nearly a decade later, Dr. Wong is recognized as one of the leading TSC researchers using the mouse model of TSC to better understand what causes epilepsy in humans and how to treat it. He and other TSC researchers are working toward unlocking the mysteries of TSC to find a cure.

A “Clinic Without Walls” Model

Dr. Wong describes his clinic as being similar to the “clinic without walls” model, which Dr. Michael Frost conceived for his TSC clinic in St. Paul, Minnesota. He, like Dr. Frost, is board-certified in child neurology and clinical neurophysiology. Dr. Wong thinks of his role as a “gatekeeper” for children affected by TSC by offering a more efficient, comprehensive, and coordinated approach for screening and evaluating individuals with TSC than a primary care practice. Those individuals with non-neurological issues are referred to colleagues within the WUSTL/Children’s network of affiliated healthcare providers.

Bench Side to Patient Care

Dr. Wong has a unique perspective in seeing the disease of TSC from the research he conducts in his laboratory as well as in his TSC clinic where he sees how individuals with TSC are affected. His clinic follows about 75 individuals with TSC. Sometimes the wait list to get an appointment in the TSC Clinic may be up to 3 months, but if it’s medically necessary an appointment is scheduled in Dr. Wong’s epilepsy clinic so they are seen sooner. His nurse, Christine, shares an insight into how much he cares about his patients, “Dr. Wong takes all the time the individual with TSC and their family needs to spend during their appointment.” In order to maximize this doctor-patient time, his office requests that medical records be sent to him to preview in advance of their appointment.

Dual Role for a Clinical Nurse Coordinator

Christine Immken, R.N., C.P.N. has been in nursing for 10 years, with most of it spent in neurology and pediatric epilepsy. She is the Clinical Nurse Coordinator for the Epilepsy Unit and recently assumed the additional role of coordinator of the TSC Clinic. The WUSTL pediatric neurology office triages TSC-related telephone calls to her and she is with Dr. Wong at the monthly clinic appointments. She prepares for each clinic by reviewing the patient’s last visit, last phone notes, current
medications, and also reviews whether or not they are due for a follow-up brain MRI, renal ultrasound, or other diagnostic test, so that these tests can be coordinated with the appointment to “save them another trip to the hospital if possible!”

**The Community Alliance Partnership**

One of the ongoing goals of the TS Alliance is to strengthen the relationship between the Community Alliances and the TSC clinics. René Friedel, the mother of a child with TSC and currently the Chair of the TS Alliance of St. Louis & Southern Illinois, began to build a solid relationship between the local volunteer branch and the WUSTL TS Clinic shortly after it opened by collaborating with Dr. Ess to initiate a TSC outreach program at the clinic. With his support (and later Dr. Wong’s) and by going through the Children’s Hospital Volunteer Program, she has volunteered hundreds of hours to provide families with “calmness, hope and positive feedback and in addition, information about what the TS Alliance does locally and nationally.” Dr. Wong values her dedication to the program and considers it one of the special services that their clinic is able to provide to individuals with TSC and their families.

“I am very proud to be working with Dr. Wong and Christine,” says René. She recounts a remarkable experience that happened when she wondered if she was making a difference to anyone. During one clinic, she met with a family who lived in a very rural area. She talked for about an hour with the mother who was very despondent about the future for her 6-month old with TSC. About 8 months later this mother passed René in the hospital corridor and smiled at her and asked if she remembered her. René recalled how wonderful she looked compared to the time when they talked in clinic. The mother told her how grateful she was for the hope and new perspective she gave to her.

For more information about the TS Clinic at Washington University call (314) 454-6120 and speak with Christine Immken, R.N., C.P.N.
Recent research from investigators at Cincinnati Children’s Hospital Medical Center shows that a substance in the blood may be useful in the diagnosis of women with sporadic lymphangi-oleiomyomatosis (S-LAM) and for those with LAM associated with tuberous sclerosis complex (TSC). These investigators found that a serum VEGF-D level of greater than 800pg/ml in a woman with typical cystic changes on high resolution CT (HRCT) is diagnostically specific for S-LAM and identifies LAM in women with TSC. A negative VEGF-D result does not exclude the diagnosis of LAM. The utility of serum VEGF-D testing in males or in women who do not have cystic lung disease on HRCT is unknown.

Why is this important and what is a biomarker? A biomarker, or biological marker, is defined by the National Cancer Institute, National Institutes of Health, as a biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition. A biomarker can be an used as important tool to use in clinical care of individuals and/or to study the response to a specific treatment in clinical trials instead of using imaging or other expensive tools.

The best known example of a biomarker is the prostate-specific antigen (PSA) that is an indicator of the presence of prostate cancer in men. PSA is a protein produced by cells of the prostate gland and is measured by testing the levels of PSA in the blood. Recently, studies have shown that the level of PSA in the blood does not always correlate with presence of cancer and/or the progression of disease, but reduction in the level of PSA in men being treated for prostate cancer is a good biomarker for the response to treatment.

If there were reliable and accurate biomarkers for TSC and LAM, it would be possible to diagnosis TSC and/or LAM through a blood test, as well as to measure the progression of the disease as well as response to treatment through a blood test. Today, expensive imaging studies are required to look at reduction of the size of tumors in the brain, kidney and lungs in response to treatment. VEGF-D may become a good biomarker for individuals with LAM, but further research will be needed to see if it will be a reliable biomarker in men and for other manifestations of TSC besides lung involvement or LAM.

Upcoming Major Events

**TS Alliance of the Carolinas**
October 2, 2010
Lake Murray Dam, Lexington, SC
Christi Davis; thechristi75@hotmail.com

**TS Alliance of Delaware/Lehigh Valley**
September 25, 2010
Gring's Mill, Wyomissing, PA
Shelly Richards; mom2ashlin@yahoo.com

**TS Alliance of Florida**
October 23, 2010
Crandon Park, Key Biscayne FL
Vanessa Vazquez; VanessaVazquez@bellsouth.net

**TS Alliance of Heartland**
October 16, 2010
Raccoon River Park, W. Des Moines, IA
Cindy & Ryan Blackard; cblackard@yahoo.com

**TS Alliance of Metro DC**
Date: TBD
Plaza in downtown Silver Spring, MD
Nathalie Simoneau; yvesnat@verizon.net

**TS Alliance of Middle Tennessee**
October 16, 2010
Centennial Park Event Shelter, Nashville, TN
Amy Hobbs; amyghobbs@aol.com

**TS Alliance of New York & New Jersey**
September 11, 2010
Onondaga Lake Park, Liverpool, NY
Stephanie Langstaff; sclangst@syr.edu

September 25, 2010
Wantagh Park, Wantagh, NY
Denise & Rob Spear; rspear96@gmail.com

New Jersey – TBD
James Richter; jrichter@winston.com

**TS Alliance of Northern California**
Date: TBD
Sacramento, CA
Suki Maharaj; sukimaharaj@hotmail.com

**TS Alliance of Ohio**
September 26, 2010
Roman Park, Westlake, OH
Michelle Blood; bblood@aol.com

**TS Alliance of Wisconsin**
Date: October 2, 2010
Grant Park, S. Milwaukee, WI
Pam Sztukowski; pamchef@wi.rr.com

**National Presenting Sponsors**

**National Honorary Chair – Julianne Moore**

**Find Out More Online**
Go to www.StepForwardtoCureTSC.org to register for a walk in your area and be sure to check out all our new online walker tools, like sample emails to help you raise money, team leader kits, walker participation packets and much more.

**Organize a Walk in Your Community**
Find out how you can stage a Step Forward to Cure TSC event in your local area by contacting Jenny Smiley at (800) 225-6872 or jsmiley@tsalliance.org.
Thanks to the generous support from The Cowlin Family Fund and the Robertson Foundation, the TS Alliance is implementing a new TSC Drug Screening Program. This program is designed to fast-track potential new treatments for TSC from the laboratory into testing in animal models of TSC and into clinical trials. The pharmaceutical industry calls this the drug pipeline that goes all the way from the initial idea to test a compound or a drug, through the animal testing to make sure it is safe and effective in model systems of TSC, and then through clinical trials and eventually and hopefully approval by the Federal Drug Administration. From beginning to end, this process can take up to 15 years and cost more than $15 million – for just one drug! However, the process is in place to make sure that drugs that are approved by the FDA are safe and effective for the indication they are approved for.

Currently, the TS Alliance is reviewing applications for the TSC Drug Screening Program and the new awards will be announced in July 2010. There are many ideas for testing already FDA-approved drugs in TSC model systems, as well as new compounds that are in development.

Two new avenues of research that are being tested in TSC model systems are:

1. A recent report showed the medication metformin, an FDA-approved drug for the treatment of type 2 diabetes, may be helpful in treating TSC, but it has a different mechanism of action than was previously understood. Rather than acting directly on the protein mammalian target of rapamycin (mTOR), metformin works through a different pathway (see the diagram modified from Kalender et al., 2010). This may be another potential treatment for TSC.

2. Glutamate is an amino acid that is found throughout the body, but is especially important as an excitatory neurotransmitter in the brain. Many companies are developing drugs that block the action of glutamate, which may be especially important in epilepsy and for some forms of intellectual disability. A recent New York Times article described the use of this class of compounds to treat Fragile X, and a 2009 study also tested this class of drugs in a pilot trial. TSC research in this area is focused on identifying whether or not these drugs might also be beneficial in animal models of TSC where seizures are prominent, as well as for learning, memory and other cognitive issues.

References


4E-PB1 = Initiation Factor 4E-Binding Protein 1
AICAR = 5-aminoimidazole-4-carboxamide-1-b-D-ribofuranoside
AMPK = AMP-activated Kinase
IRS = Insulin Receptor Substrate Family
mTOR = mammalian target of rapamycin
PKB = Protein Kinase B (AKT)
Rag proteins = Family of four related small guanosine triphosphatases (GTPases)
S6K1 = S6 Kinase 1
TSC1/2 = Tuberoous Sclerosis Complex proteins 1 and 2
Honorariums (January – March 2010)

You can honor a friend or family member for an important occasion with a gift to the TS Alliance. It is a wonderful way to send a birthday or anniversary wish, or congratulations for retirement, a job well done, graduation, etc. Please include the name and address of the individual being honored so that acknowledgement of your kind donation can be sent. Tuberous Sclerosis Alliance honorarium cards are also available if you would like to make a gift in honor of family, friends, or colleagues. To receive tribute cards, call Tye Hoffman at (800) 225-8687 or by email at thoffman@tsalliance.org. In addition you can also create your fundraising page in honor of a special occasion at www.tsalliance.org.
Memorials (January – March 2010)

Contributions are given to the Tuberous Sclerosis Alliance at the request of family members in memory of their loved ones. We extend our sympathies to the family and friends of those memorialized below. These generous contributions support the progress of our mission to find a cure for tuberous sclerosis complex.

Tribute(s) for Anna Russell
Mr. and Mrs. Valentine J. Pust

Tribute(s) for Emory Shapses
Mr. and Mrs. Marc Shapses

Tribute(s) for Madalyn Scherer
Mr. and Mrs. Michael Schneider

Tribute(s) for Carter Schmidt
Ms. Amy L. Fox

Tribute(s) for Greyson R. Schwaigert
Mrs. Lindsey Hamilton

Tribute(s) for Kylie Seggerman
Ms. Nadine A. Klemens-Gilmore

Tribute(s) for Benjamin Shapiro
Mrs. Caroline Kuntz Mr. Trish Modabber

Tribute(s) for Henry P. Shapiro
Mr. Simon Groner

Tribute(s) for Drew Sklarin
Mr. and Mrs. Larry Donsky

Tribute(s) for Olivia Smiley
Insulation Products Corp

Tribute(s) for Lillian R. Solise
Mrs. Erika Jones Anonymous

Tribute(s) for Suzanne Stoll
Mr. and Mrs. Paul A. Schumacher

Tribute(s) for Emily B. Szilagyi
Mr. and Mrs. Jerome Aroesty
Mrs. Diane Burgess Dr. and Dr. Malin Dollinger
Ms. Sandra A. Edwards
Mrs. Linda C. Eifood
Mr. and Mrs. Reiner Labruff
Mr. Greg Lenahan Mrs. Malka L defineshal
Mr. and Mrs. Larry Meyers Dr. Eric Small

Tribute(s) for Chandlee Taylor
Mr. and Mrs. Kevin R. Coneys

Tribute(s) for Makenna G. Turner
Mr. and Mrs. Harold C. Podgorski

Tribute(s) for Kurt T. Ulrich
Ms. Anita Ulrich

Tribute(s) for Ryan Ventimiglia
Washington Street School

Tribute(s) for Eli Warner
Mr. and Mrs. Thomas E. Howie

Tribute(s) for Addylyn Wenger
Mrs. Karen Johnson-Wenger

Tribute(s) for Kalla E. Windham
Ms. Donna G. Howard

Tribute(s) for John A. Alukonis
Mr. and Mrs. David Brahm
William Kamienie Mr. and Mrs. Kenneth Toki

Tribute(s) for Harold L. Aronson
Ms. Melinda Snyder

Tribute(s) for Bernard Beem
Mrs. Heidi Anderson

Tribute(s) for Celia Burack
Mrs. Naomi Childers Mr. and Mrs. Stanley Worton

Tribute(s) for Mary B. Ciliberti
Mr. Ronald Sironen

Tribute(s) for Winnie Counts
Mr. and Mrs. Marion S. Adams, Jr.

Tribute(s) for Cecile Crowell
Ms. Genevieve M. Carter
Classic Cuts
Mr. and Mrs. Theodore J. Crowell Mr. and Mrs. Glenn A. Foster Ms. Peggy A. Gettys
Mr. and Mrs. David L. Roy Mr. and Mrs. Wilfred J. Roy Ms. Sandy Weston

Tribute(s) for Sylvia Cushing
Mr. and Mrs. Marion S. Adams, Jr.

Tribute(s) for Richard Denton
Mrs. Sue Bennett Ms. Virginia T. Chapman and Ms. Diane Chapman
Mr. Anthony Mazzamuto

Tribute(s) for Cork Enslin
Mr. and Mrs. Gerald E. Enslin

Tribute(s) for Heidi Erb
Mr. and Mrs. Robert E. Gendreau

Tribute(s) for Rose Glanzberg
Mr. and Mrs. Mel Charest

Tribute(s) for Henry Grider
Ms. Mary Alice Gudie

Tribute(s) for Hubert Hensley
Ms. Frances I. Paden

Tribute(s) for Joseph Herman
Mr. and Mrs. Robert Hockstein

Tribute(s) for Thomas W. Kety
Mrs. Judy Boatwick

Tribute(s) for Mark Luebbe
Mr. and Mrs. Rodney J. Weeks

Tribute(s) for Michael Mac Ginley
Mr. Daniel Doyle

Tribute(s) for Michael Mac Ginley
Mrs. Mary Kennedy Mr. and Mrs. Daniel Mac Ginley
Dr. William Tatum
Mrs. Betty Truncale

Tribute(s) for Elizabeth Nelson
Mr. Greg Linsin and Ms. Julie A. Blum
Ms. Kari Luther Carlson
Mr. Ted DelBraga
Ms. Alice Easterling
Mr. and Mrs. Frederick E. Fisher
Dr. Elizabeth P. Henske
Mr. and Mrs. Abe Mastbaum
Ms. Eva Monastery Ms. Mary Rouse

Tribute(s) for Rita Okun
Mr. and Mrs. Robert Hockstein

Tribute(s) for Soleil L. Pilgrim
Mr. Jim Ham and Ms. DJ Pace

Tribute(s) for Lydia Quinones
PC Doctors of Tamarac

Tribute(s) for Frank J. Reilly
Mr. Andrew Hunter

Tribute(s) for Carson Russell
Mr. and Mrs. Richard E. Allen Ms. Phyllis Atkinson Ms. Shelley Boyd
Mr. and Mrs. Charles D. Brigham
East Haven Police Union
Mr. Michael Fitzpatrick
Mr. and Mrs. Kevin Foote
Ms. Judi Feucht
Mrs. Lee Ann Gamble Mrs. Catherine Gazikas
Gem Environmental
Mrs. Kristi Hopper Mr. and Mrs. Maurice Keane
Mr. and Mrs. Chris Kohneke
Mr. and Mrs. Albert Krupski
Lamb & Barnosky, LLP
Mr. and Mrs. Louis Moffa
Mr. Ronald A. Muhe
Peconic Ophthalmology PLLC
Mr. and Mrs. Valentine J. Pust
Mr. and Mrs. Harry Risberg
Mr. Edward J. Rongling
Ms. Carol A. Rossi
Mr. and Mrs. Chris Russell
Mr. Bruce Scobie
Ms. Gloria Shirvell
Mrs. Barbara Siegel
Southhold Voice, Inc
Mr. Nicholas S. Tsounis

Tribute(s) for Chris N. Stamulis
Mrs. Kristin Beddoo
Mr. and Mrs. Jim Burns
Mr. and Mrs. Robert C. Childers Mr. and Mrs. Helen Everhart
Ms. Ruth C. Feldewerth
Ms. Joan James
Mr. and Mrs. John N. Jouriles
Mr. and Mrs. Nick Sallas
Mr. and Mrs. Pete J. Sallas
Mr. and Mrs. James T. Shelton

Tribute(s) for Haley Stovall
Ramey, Inc
Smith Brothers Tree Farm
Ms. Nancy M. Stovall

Tribute(s) for Suzanne Strom
Mr. and Mrs. Alfred Rosenfeld

Tribute(s) for Rose Mary Sullivan-Carollo
Mr. and Mrs. R. Tom Bartoletti
Mr. and Mrs. Alan D. Brown
Mr. and Mrs. Robert L. Carroll
Mr. and Mrs. Erma Davis
Mr. and Mrs. Gerald Jette Mr. and Mrs. David Munson
Mr. and Mrs. Edmund Olszewski
Ms. Catherine R. Rice Ms. Dorothy J. Salmonson

Tribute(s) for Irene Tewis
Mr. and Mrs. Joan Gohn

Tribute(s) for Margaret C. Waits
Mrs. Amy Barlow
Ms. Jane Fox
Mr. and Mrs. J. David Fraelay
Mr. and Mrs. Jack G. Gray
Mr. and Mrs. David Johnson
Ms. Mary L. Patterson and Ms. Susan M. Anderson
Mr. and Mrs. Tim Straussel
Ms. Louise Westbrook

Tribute(s) for Marilyn Ward
Mr. and Mrs. Alan Freeman

Tribute(s) for Kathleen Williams
Ms. Tracy Wilson

Tribute(s) for Margaret M. Williams
Mr. and Mrs. Glen A. Call Mr. and Mrs. John G. Fordney
Out of My Mind
by Sharon M. Draper

Synopsis: Eleven-year-old Melody has a photographic memory. Her head is like a video camera that is always recording. Always. And there’s no delete button. She’s the smartest kid in her whole school but no one knows it. Most people her teachers and doctors included don’t think she’s capable of learning, and up until recently her school days consisted of listening to the same preschool-level alphabet lessons again and again and again. If only she could speak up, if only she could tell people what she thinks and knows . . . but she can’t, because Melody can’t talk. She can’t walk. She can’t write. Being stuck inside her head is making Melody go out of her mind that is, until she discovers something that will allow her to speak for the first time ever. At last Melody has a voice . . . but not everyone around her is ready to hear it.

Think College! Postsecondary Education Options for Students with Intellectual Disabilities
by Meg Grigal, Debra Hart

Synopsis: As the Higher Education Opportunity Act opens the door to more options and supports, more and more students with intellectual disabilities are “thinking college.” That means high schools, colleges, and universities must be fully prepared to meet the needs of students with disabilities—and this comprehensive resource is just what they need. Developed by two of the most respected experts on this hot topic, this book uncovers the big picture of today’s postsecondary options and reveals how to support students with disabilities before, during, and after a successful transition to college.

A critical resource for education professionals to read and share with families, Think College helps readers

• understand the three current models for postsecondary education (PSE): inclusive individual supports; substantially separate, noninclusive classes; and hybrid approaches

• overcome the common challenges and barriers to PSE for students with significant

• plan effective, person-centered transition services for high school students as they pursue PSE

• support students as they manage the practical aspects of a positive PSE experience (see box)

• connect students’ PSE experiences directly to employment and their other individual life goals

• discover how exciting legislation and policy changes will affect future PSE options

Throughout the book, vignettes and first-person narratives from students and families underscore the benefits and challenges of PSE, and detailed profiles of real programs illustrate what a wide range of postsecondary options look like.

Readers will also get the helpful tools they need to create effective programs and ease students’ transition
to PSE, including a self-advocacy checklist, a program evaluation tool, sample student schedules, and a college-planning checklist for students and families.

With this thorough guide to today’s PSE options and tomorrow’s possibilities, professionals will help students with intellectual disabilities take full advantage of their educational opportunities—and set the stage for a successful, fulfilling community life.

**The Leisure Seeker**

by Michael Zadoorian

**Synopsis:** John and Ella Robina have shared a wonderful life for more than fifty years. Now in their eighties, Ella suffers from cancer and has chosen to stop treatment. John has Alzheimer’s. Yearning for one last adventure, the self-proclaimed “down-on-their-luck geezers” kidnap themselves from the adult children and doctors who seem to run their lives to steal away from their home in suburban Detroit on a forbidden vacation of rediscovery.

With Ella as his vigilant copilot, John steers their ’78 Leisure Seeker RV along the forgotten roads of Route 66 toward Disneyland in search of a past they’re having a damned hard time remembering. Yet Ella is determined to prove that, when it comes to life, a person can go back for seconds—sneak a little extra time, grab a small portion more—even when everyone says you can’t.

Darkly observant, told with humor, affection, and a touch of irony, *The Leisure Seeker* is an odyssey through the ghost towns, deserted trailer parks, forgotten tourist attractions, giant roadside icons, and crumbling back roads of America. Ultimately it is the story of Ella and John: the people they encounter, the problems they overcome, the experiences they have lived, the love they share, and their courage to take back the end of their own lives.

**Anything But Typical**

by Nora Raleigh Baskin

**Synopsis:** Jason Blake is an autistic 12-year-old living in a neuro-typical world. Most days it’s just a matter of time before something goes wrong. But Jason finds a glimmer of understanding when he comes across Phoenix Bird, who posts stories to the same online site as he does.

Jason can be himself when he writes and he thinks that Phoenix Bird—her name is Rebecca—could be his first real friend. But as desperate as Jason is to meet her, he’s terrified that if they do meet, Rebecca will only see his autism and not who Jason really is by acclaimed writer Nora Raleigh Baskin, this is the breathtaking depiction of an autistic boy’s struggles—and a story for anyone who has ever worried about fitting in.

**Transition Education and Services for Students with Disabilities**

by Patricia L. Sitlington, Gary M. Clark, Debra Neubert

**Synopsis:** The Individuals with Disabilities Act of 2004 is making substantial changes in the planning and delivery of transitional services. In addition, more
elementary and middle school children are receiving services. Both situations are reflected in this edition, along with a new focus on getting students ready for their lives as adults as well as preparing them academically. Chapters address legislation, families, and the formative K-8 years, program elements such as assessment, transition to college or employment and independent living, resources, and program implementation techniques. Annotation ©2004 Book News, Inc., Portland, OR

More than a Job: Securing Satisfying Careers for People with Disabilities

by Paul Wehman (Editor), John Kregel, John Kregel

Synopsis: This consumer-driven book provides professionals with step-by-step strategies for helping people with physical and developmental disabilities find meaningful employment. Emphasizing the importance of long-term planning and individualized control over assessment and training, this practical resource lays out guidelines for pinpointing consumer interests, charting a career path, and identifying employment options. The editors and chapter authors, many of whom have disabilities themselves, also discuss issues such as transition from school to adult life, transportation, social relationships, and community access. For employment specialists, secondary special education teachers, work-study personnel, advocates, and rehabilitation counselors and therapists, this resource facilitates the day-to-day support that people with disabilities need as they strive to achieve their own personal career goals.

New Edition of Tuberous Sclerosis Complex Book Now Available

Tuberous Sclerosis Complex: Genes, Clinical Features and Therapeutics

Edited by David J. Kwiatkowski, Vicky Holets Whittemore, Elizabeth A. Thiele
ISBN: 978-3-527-32201-5
Hardcover · 432 pages · Published April 2010

This book offers a comprehensive overview of the molecular basis and clinical features of the genetic disorder tuberous sclerosis complex (TSC). Special focus is placed on novel insights into the signal transduction pathways affected by the disease, genotype-phenotype correlations, recent clinical discoveries and understanding, while existing and potential therapies are also discussed in depth. The editors are leading experts in research, treatment, and advocacy of the disease. Visit www.wiley.com to find out more about the editors, view the Table of Contents and place an online order. List price is $119.95, but you can get a special 20 percent discount ($95.96) by using the promotion code LIFE when ordering.
by including the TUBEROUS SCLEROSIS ALLIANCE ENDOWMENT FUND in your will, trust or charitable gift annuity.

For more information about making a planned gift, contact Kari Luther Carlson at (800) 225-6872 or visit tsalliance.org/plannedgiving